

# Online Social Networks for patient involvement and recruitment in Clinical Research?

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## **Abstract**

### *Aims*

This paper reviews current literature and discusses the potential for Social Networking websites for engaging patients and the public along with recruitment and retention of participants in clinical research.

### *Background*

In the UK (United Kingdom) alone 80% [21 million] of households now have internet access; an increase of 3% 12 months (ONS, 2012). Social Networking websites are becoming a large influence on daily lives and can be defined as “an online location where a user can create a profile and build a personal network that connects him or her to other users” (Lenhart & Madden, 2007).

Clinical research faces several challenges, with increasing need to engage with patients and the public and studies requiring increasing numbers of participants along with retention in studies. More innovative methods of recruiting participants could aid in the participation and follow up from under-served, under-represented or hard to reach groups/communities.

### *Data Sources*

Searches were conducted using EMBASE, BNI, ERIC, CINAHL, PSYCHinfo online databases and Google Scholar to identify any grey or unpublished literature that may be available.

### *Review Methods*

This is a methodology paper.

### *Discussion/Conclusion*

Key findings suggest that this is a successful, cost effective and efficient method by which to target and recruit a wide range of communities, adolescents, young people and underserved populations into quantitative and qualitative research. Retention of participants in longitudinal studies could be improved with the use of Social Networks such as Facebook. Current evidence would indicate that a mixed approach to recruitment using Social Networking and ‘traditional’ methods is most effective.

### *Implications for Practice/Research*

Further research is required to strengthen the current evidence available, especially with regards to dissemination of research through Social Networks. Researchers should consider using Social Networks as a valid method of engaging the public and also for recruitment and follow-up of participants.

**Keywords:** Social Networks, Research Participants, PPI, Research Recruitment

## **Introduction**

Technology is a large part of everyday life. In the United Kingdom [UK] alone 80% [21 million] of households now have internet access; an increase of 3% in the preceding 12 month period (ONS National Statistics Online, 2012).

Social Networking Sites can be defined as “an online location where a user can create a profile and build a personal network that connects him or her to other users” (Lenhart and Madden, 2007). Users are able to upload photos, videos and share information about themselves with friends. There is often also the facility for creating and being members of ‘groups’ where people who share a common goal and/or interest can network. Privacy settings are controlled by each user and group creator and can be changed at any time with little effort.

Social networking sites such as Facebook and MySpace have not typically been embraced by all; with some colleges and larger organisations [including the NHS] even blocking their use. The use of Facebook has also raised professional issues with regards to professional accountability and boundaries. Particularly in Nursing, the NMC (Nursing and Midwifery Council) have previously suspended members due to Facebook activity, with repeated warnings to all members regarding such activity, issued in subsequent years (Nursing Standard, 2008; 2008a; Middleton, 2011; Practice Nurse, 2011).

Since its establishment in 2004 Facebook (accessed 18/11/09) claims to be “Giving people the power to share and make the world more open and connected”. Facebook is the largest international social networking site and boasts 835 million users worldwide; in excess of 12% growth from 2011-2012. The UK accounts for 32.5 million Facebook users; close to 52% of its total population (Internet World Stats, 2012).

Mobile technology has also become a large part of daily life, with individuals across all age ranges accessing social network sites and the internet via mobile or ‘smart’ phone; an increase of more than 100% since 2009. This enables individuals to access the internet almost anywhere as long as they have the mobile device with them, highlighting the ‘real time’ and improved accessibility potential. Whilst 91% of individuals of 16-24 years participating in social networking online, there has been a steady increase in all age groups. Consequently, ONS (2012) shows that internet usage is no longer dominated by the 16-24 year old age group and that social networking in particular has increased in usage by 40%, suggesting the potential to reach a broad and diverse audience.

BBK Media (2011) suggests that there are three key roles for Social Media in a Clinical Trial Environment 1) Listening 2) Informing 3) Engaging. Listening involves methods which assist in information gathering from activities, language through blogs, message boards. Informing relates to providing information to specific groups of individuals through targeting portals such as social media adverts and research study websites. Finally, engaging uses online patient communities for open discussion, messaging and other options such as YouTube.

Two key aspects of clinical research which encompass these three roles are identified for the purposes of this discussion a) engaging patients and the public to participate in research b) retention and recruitment of participants. This article aims to discuss these aspects and the how the use of

social networking websites such as Facebook may contribute to these in the context of clinical research.

### **Patient and Public Involvement in Clinical Research**

Best Research for Best Health (2006), Equity and Excellence: Liberating the NHS (2010) highlight the need for increasing patient and public involvement, equality of access and dissemination of findings within clinical research. A recent pilot survey carried out by the author with the use of an online survey internet site and a snowball sample of participants from Facebook showed that a large percentage of individuals did not understand what 'Clinical Research' was.

Farmer et al (2012) identified how Facebook users with specific health related conditions connect with each other through groups and pages, and argues that clinical researchers should not overlook this as a method of accessing feedback and input from a large and diverse group of stakeholders. Their study of Facebook pages and groups found 75.6% of their sample 757 pages were patient or support groups. The nature of Facebook groups for example, means that a 'discussion' can be set up and focused on a particular question which shows potential for obtaining asynchronous focus group feedback with comments recorded as they occur; enabling easy cost-effective and efficient analysis. This may also prove to be useful in very early stages of research planning, developing research questions, but also for dissemination and feedback of findings through research project specific groups.

Given the diverse population served by social networking websites it is argued that it is a valuable tool in promoting and raising awareness of clinical research across the UK and further. Yet the evidence surrounding this is limited. A scoping search found one study focused on this; Williams (2011) who successfully used a Facebook page to share and disseminate scientific research in Sports Science.

Pfeifer (2011) argues that a wide range of quality improvement efforts in healthcare fail to engage service users successfully and suggests that policy on treatment practices should take on board patient experience. PatientsLikeMe is part funded via pharmaceutical companies but patients are free to upload and monitor their own data on signs, symptoms and side effects of medication; an advantageous method of research for both the patient and industry and one which has been shown to empower patients along with evaluating the effectiveness of drugs already in use. Conversely, Weitzman et al (2011) used data sharing software for individuals with diabetes, and enabled access via Facebook and MySpace on an international level. This enabled patterns and associations of diabetes to be identified along with associated populations on a large scale. However, limited internet access in particular demographic groups and geographic locations meant that engaging stakeholders in this manner may not be sufficient to make feedback generalizable. In the UK, ONS (2012) suggests that the 'digital divide' is slowly narrowing but there is noticeably less internet activity reported from individuals in lower socio-economic groups and those over the age of 65. Careful consideration for engaging patients and public through social networking sites needs to be observed.

Gajaria et al (2011) was able to successfully use Facebook to identify and obtain feedback from groups of individuals with Attention Deficit Hyperactivity Disorder [ADHD]; however the validity and accuracy of this was significantly difficult to confirm and relied upon self-reported diagnosis within the membership of the Facebook group. This suggests that social networking sites may be useful to engage the public but may only be appropriate for specific activities in the context of clinical research. For example, Jones et al (2012) and Amerson (2011) successfully used this method in combination with traditional face to face methods to enable successful follow up of participants.

### **Recruitment and Retention of participants**

Wilson et al (2012) outline some of the potential methods for using Facebook in the Social Sciences in particular, and suggests that a wide range of quantitative and qualitative approaches are possible along with recruitment methods including, offline recruitment and follow-up, use of Facebook applications and advertising, and data crawling by using profile data. More specifically, BBK Media (2011) identifies the key arenas for targeting groups for recruitment of participants:

- Behavioural – adverts for users based on content searches and time spent on topics
- Contextual – adverts for users based on searches within specific websites
- Demographic – used where patients and the public have personal profiles such as Social Networking sites
- Geographic – adverts are provided based on the location of the user from personal profiles on Social Network sites or IP address

This ‘targeting’ method is advocated by companies such as Acurian (a recruitment company for clinical research) have set up an application – Click it Forward - by which the public can share support for clinical research through Facebook and similar social networking pages; bringing in the concept of ‘snowballing’ for increasing recruitment and electronic surveys. They claim that 20% of their recruitment activity in clinical trial studies comes from such routes. Kapp et al (2010) highlighted how this method of recruitment enabled recruitment of women aged 35-49 years but warned about the challenges of developing adverts which foster interest in the target population along with motivating people to continue. In addition, snowball sampling can produce larger sample sizes this carries the risk of identifying participants who do not fit inclusion criteria or large numbers of participants from specific demographic or geographic locations when a more diverse cross-sectional sample is required.

#### *Targeting communities and groups*

Garland et al (2011) worked in partnership with Facebook in order to ‘target’ an advertisement for

their project survey to individuals who met a particular demographic [females, 16-25 years old]. Advantages of targeted advertising meant that recruitment and frequency of marketing could be scaled up or down depending on response rate. However, Kapp et al (2010), Ramo et al (2010) and Ramo and Prochaska (2012) suggested that this method of targeted recruitment should be carefully constructed. In Ramo et al (2012), Facebook were very clear to 'approve' adverts before use, illegal activity and the promotion of tobacco products is strictly prohibited and this therefore, limited the reach of the adverts within the target population of 16-25 years. Conversely, following a study surveying college students and prescription opioid misuse Lord et al (2011) suggests that validity indicators are essential in order to ensure reach of the original 'target' population.

Responses within Garland et al (2011), Lord et al (2011) and Ramo et al (2010) showed that individuals were comfortable answering sensitive questions on topics such as drug misuse, tobacco use, infertility and Human Papilloma Virus [HPV] suggesting that the anonymity provided online is acceptable to participants within survey based research. More complex approaches such as the International Diabetes Database Social Network used by Weitzman (2011) showed that individuals who practiced poor compliance with treatments or risky behaviours were less likely to provide information.

#### *Recruitment and Retention in 'hard to engage' populations and longitudinal studies*

A range of research studies have shown that social networking sites as recruitment sources can help to engage individuals from traditionally 'hard to reach' or 'at risk' populations using targeted sampling, but also to stay in contact with individuals who may be geographically mobile and change their contact details frequently [such as Travellers] (Amerson, 2011; Garland et al, 2011; Mychasiuk and Benzies, 2011; Ramo and Prochaska, 2012; Lord et al, 2011; Fenner et al, 2012). In support of this, Jones et al (2012) and Mychasiuk and Benzies (2011) showed high retention rates in longitudinal studies which traditionally result in high losses to follow up due to the periods of time



involved. Mychasiuk and Benzies (2011) reduced loss to follow up by 16% through the use of Facebook as a method of communication. However, Fenner et al (2012) found that individuals in the highest brackets of socio-economic advantage were 50% more likely to access a study website than those from the lowest socio-economic group. This possibly highlights that the 'targeting' method used in Fenner et al (2012) is more favourable as a follow-up method rather than initial recruitment for lower socioeconomic groups, and those from 'hard to reach' populations.

Several other studies have successfully used social networking websites to recruit adolescents and young people between the age of 18-25 (Ramo et al, 2010; Ramo and Prochaska, 2012; Jones et al, 2012; Lord et al, 2011;). Along with the study by Fenner et al (2012) it was found that the use of Social Networking websites with geographic and demographic targeting methods could increase sample sizes along with the diversity of participants, reduce the time period of recruitment and reduce costs associated with traditional methods of recruitment.

#### *Representativeness of population sample*

The sample obtained in Garland et al (2011) included participants from rural, regional and urban locations and proved to be representative of the target population. Interestingly, this study found that women over the age of 18 were significantly more likely to complete the survey than those in the 16-17 year age group [ $p > 0.05$ ], suggesting that it may be a more appropriate method to recruit adult participants rather than young people under 18. This significance was also found by Fenner et al (2012) and Jones et al (2012) but this was reliant on the study design, targeting method and inclusion criteria, and further research is needed to identify whether such methods recruit representative samples and if indeed samples are subject to participation bias. In addition, Gajaria et al (2011) clearly identified the limitations through recruitment in Facebook user groups and the inability to confirm declared age, demographic or diagnostic status. In light of these studies, the need for a blended approach between 'traditional' and 'online' methods of recruitment along with

high quality documentation regarding recruitment sources to optimize research is identified.

### **Implications for use of Social Media**

Ofcom (2008) highlighted that 49% of 8-17 year olds have a profile on a Social Networking website. Typically, the minimum age limit for registration with a Social Networking site is 13 and yet 27% of 8-11 year olds declare that they have a profile. This suggests that some individuals are bypassing security questions by submitting an erroneous age. Consideration is needed with regards to informed consent to research using Social Networking sites, but also the true representiveness of samples obtained through anonymous participation as found by Gajaria et al (2011). Where young people are concerned, safeguarding should be considered and clear procedures outlined for all parties.

The issue of informed consent is outlined and addressed by Abdesselem et al (2011), Bull et al (2010) and Zimmer (2010). Particularly when targeting young people and adolescents there should be a clear outline of the research, data to be obtained and confidentiality. However, it is argued that this should be considered and accounted for in all clinical research projects and should reflect individual project methodology in accordance with national and local guidelines. For example, Bull et al (2010) targeted a young and vulnerable population and obtained information from Facebook profile posts and therefore, ethical considerations were different to those required by Mychasiuk and Benzie (2011) who utilized Facebook as a follow-up method, or the project by Fenner et al (2012) where a simple survey was administered. Procedures for withdrawing consent and associated collected data also need to be considered.

Bull et al (2010) operated within research ethics guidelines and also obtained detailed information about the privacy settings associated with the Social Networking website being used. Researchers need to be mindful that, young people in particular may often be unaware of the risks associated

with Social Networking websites and methods should be incorporated to provide support and advice on this prior to participation. Bull et al (2010) also advise that all data collected should be transferred and analysed outside of the network being used to avoid 'creep' into any other postings. Where using a study specific Facebook group, researchers should provide guidance on what is deemed to be inappropriate behavior, monitor discussions and have procedures for removing potentially offensive or damaging posts. Social Networking sites now have extensive security and privacy policies which are intended to protect users – including researchers (such as the example of targeted advertising in Ramo and Prochaska (2012) and Ramo et al (2010)), along with this the Internet Research Ethics website outlines clear guidelines when conducting research on the internet and several studies have also examined this in more detail (Mazur, 2010; Zimmer, 2010).

## **Conclusion**

The evidence available for the use of Social Networking websites in clinical research is limited at present. However, current research suggests that it is cost effective, efficient and successful in engaging a diverse range of individuals for initial user feedback, recruitment, follow-up and possibly dissemination. Most commonly, female participants within the 18-25 year old age range respond to targeted advertising of research, along with individuals from middle to higher socio-economic groups. The potential use of Social Network websites in decreasing loss to follow up in 'at risk' or highly mobile populations is also demonstrated. There are a variety of methods by which Social Networking websites may be used for engaging, listening and informing including the use of personal profile posts/discussions, creation of open or closed groups, utilization of current groups/pages and targeted advertising.

This paper was not focused on discussing ethical implications of using Social Networking websites in clinical research, although some concerns surrounding consent and privacy have been identified. A

detailed knowledge of the chosen Social Networks privacy settings and options available such as groups, pages or profiles should be considered and justified clearly before embarking on any form of clinical research project.

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